September 30, 2018

Global Leukodystrophy Initiative (GLIA)
Rare Diseases Clinical Research Consortia for the Rare Diseases Clinical Research Network (U54)
Funding Opportunity Announcement (FOA) Number: RFA-TR-18-020

To Whom It May Concern:

It is with great enthusiasm that I write to acknowledge the PMD Foundation's support of the Global Leukodystrophy Initiative (GLIA) and their application to the Rare Diseases Clinical Research Network (RDCRN), cooperative network intended to promote clinical research in the rare diseases.

The PMD Foundation played an integral part in the initial creation of GLIA and was a co-sponsor of the GLIA launch meeting in 2013. The PMD Foundation has continued our support of GLIA by Co-hosting the meetings held in 2015 and 2017. We are also committed to co-sponsoring the upcoming meeting in 2019. We have been working closely with Dr. Vanderver and her International panel of researchers over the past 9 months. Over a 6 month period we participated bi-weekly international conference calls with this panel. We worked to help establish PMD specific data collection variables that would help establish patient relevant outcomes in combination with PMD specific clinical features. The PMD Foundation is working towards funding the proposed Natural History study that this panel has created which is estimated to require a $180,000 investment. A financial commitment on this level for a small non profit organization of an ultra rare disorder like PMD is a testament to the faith and trust we place in GLIA and this panel of researchers.

We feel that the leadership and united voice that GLIA offers an ultra rare disease like PMD is critical. If we are to see advances in the science and research in these white matter diseases we need GLIA to help to move the science forward. GLIA offers our communities hope that we will see advancements and understanding and potential therapies and treatments in our lifetime. The PMD Foundation and the PMD Community whole heartedly support GLIA and their application to promote clinical research in the rare diseases.

Sincerely,

Dave Manley
PMD Foundation
Board Chair
www.pmdfoundation.org